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Analysis of definitions of resilience provided by participants resulted in the following synthesis of meaning; being resilient means adopting an attitude of striving to overcome the adversity caused by the experience of schizophrenia. The process of striving enables the person to learn about themselves, the effect of the schizophrenia illness on them, and how to manage it in the context of the life they want to live. Striving to overcome schizophrenia involves struggle, including repeated backwards steps and during this, the individual seeks out and uses supportive people and systems. Having then learned how to overcome and manage the challenges of the schizophrenia illness the individual is then able to apply the same resilient attitude to engage in new challenges and experiences to grow their life in ways unrelated to the illness. Through experiencing the severe adversity of schizophrenia, the person has learned how to be resilient.

The presentation will describe the process for becoming resilient with schizophrenia, including factors found to be supportive and factors found to be challenging to the process. An instrument for measuring the resilience of a person diagnosed with schizophrenia is being developed from the research findings.

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People with schizophrenia can become resilient while recovering

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Abstract

People diagnosed with schizophrenia who consider themselves to have recovered were interviewed to identify what they believe resilience is and how it may have been involved in their recovery.

Analysis of definitions of resilience provided by participants resulted in the following synthesis of meaning; being resilient means adopting an attitude of striving to overcome the adversity caused by the experience of schizophrenia. The process of striving enables the person to learn about themselves, the effect of the schizophrenia illness on them, and how to manage it in the context of the life they want to live. Striving to overcome schizophrenia involves struggle, including repeated backwards steps and during this, the individual seeks out and uses supportive people and systems. Having then learned how to overcome and manage the challenges of the schizophrenia illness the individual is then able to apply the same resilient attitude to engage in new challenges and experiences to grow their life in ways unrelated to the illness. Through experiencing the severe adversity of schizophrenia, the person has learned how to be resilient.

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Keywords : Resiliency, process, schizophrenia

Background

The act of trying to assimilate into the milieu of acute mental health practice as a newly graduated nurse generated a deep need to explore for answers to a range of questions, for example; why do clinical interviews to assess the mental state of a person with schizophrenia feel like hope draining experiences? Frequently emerging from the room with an empty and flat feeling prompted the question of "if it felt like that for a clinician, how did it feel for the person diagnosed with schizophrenia"? During an interview focused on looking for illness symptoms, dysfunction and other problems, how can hope for the future be generated or the possibility of a successful outcome be included? The Churchillian spirit of looking for the opportunity in the difficulties is noticeably absent. The saying "in every adversity there lies the seed of an equivalent advantage" (World of Quotes, 2011) suggests that schizophrenia, as a condition, must have some positive aspects. Could the positive aspects of schizophrenia be used to lead the person to a hopeful and optimistic future, and if so, why is knowledge of these absent in the clinical setting? The emerging field of positive psychology is based upon the premise that recognising a person's strengths and the positive aspects of their experience is necessary for rebuilding mental health (Peterson & Seligman, 2004).

Questions for discussion

The questions that needed answering were;

1) What are the positive aspects of schizophrenia and why is knowledge of them missing in the therapeutic milieu?
2) Why do clinicians demonstrate a pessimistic attitude towards the diagnosis of schizophrenia?
3) Is an optimistic outcome possible for schizophrenia?
4) What is an optimistic outcome for schizophrenia?
5) How is an optimistic outcome achieved?
6) How can this knowledge be used clinically to communicate the positive and optimistic aspects of the journey with schizophrenia?

Prior to discussing how these questions have been answered through a review of literature, the concept of schizophrenia will be discussed to allow the answers to questions to be more knowledgeably considered.

Schizophrenia

According to World Health Organisation, one person in every 1,000 people will be diagnosed with schizophrenia (Ayuso-Mateos, 2000; Access Economics, 2002). The average age of onset for males is 20 years of age and for females is 24 years of age (Saha, Chant & McGrath, 2007; Hor & Taylor; 2010; Palmers, Pankratz & Bostwick). The cause of schizophrenia is unknown. It is considered to be a genetically based condition because it aggregates in families (Maier, Rietschel, Linz & Falkai, 2002; van Os & Kapur, 2009). There is a 10% risk for developing schizophrenia from having a mother with schizophrenia and 50% risk if both parents have schizophrenia, therefore the strongest predictor of schizophrenia is an affected 1st degree relative.

Having a mother or parent with schizophrenia increases the likelihood of developing schizophrenia but is not sufficient alone to cause it. A study in Finland of siblings where one child was adopted and one child was reared by the biological mother with schizophrenia found environment to be a significant predictor in whether a 'schizophrenia break' occurred (Tienari & al. 2002).

Nine critical environment loading factors have been shown to incrementally increase risk for the development of schizophrenia. The nine factors are : 1) having an intensive or explosive atmosphere in the home, 2) not being acknowledged by parents, 3) having parents in conflict with one another, 4) having family insecurity, such as financial insecurity, 5) having a narrow range of emotional expression within the family, 6) being dissatisfied with the family, 7) experiencing poor family boundaries, and 8)

and 9) individual or generational enmeshment of problems, for example, trauma (Hafner, 2002a). Having one environmental risk factor represents no increase in risk, two factors represents a four-fold increase in risk and four factors are associated with a ten-fold increased risk over normal for development of schizophrenia when coupled with genetic risk (Hafner, 2002b).

Diagnosis of schizophrenia is made through an interview process where questions will be asked to explore the individual's thinking, perceptions, and mood. A diagnosis of schizophrenia requires the presence of two of more symptoms for a significant portion of time during a one month period and the overall presence of symptoms during a six month period (American Psychiatric Association, 2000).

Symptoms are categorised into two types; positive symptoms and negative symptoms. Positive symptoms are psychotic in nature and can be divided into two types; firstly, sensory hallucinations and delusions, and secondly, disorganised or bizarre behaviour, disorganised speech and inappropriate affect (Pull, 2002). Negative symptoms are mood related and include affective flattening, loss of motivation, flattened emotions, social withdrawal and attention impairments (Pull, 2002)

The experience of schizophrenia is highly individual to the person having it and no two people will experience the same range of symptoms (Davidson & McGlashan, 1997). More than 90% of people diagnosed will experience delusions, 50% will experience auditory hallucinations and the same individual may experience different symptoms during different episodes which is diagnostically problematic (Pull, 2002). Impairment of ability to function in one or more major life area due to the presence of symptoms is also necessary for diagnosis to be given.

Longitudinal studies have identified that between 53% and 59% (Blueler, Huber, Gross, Schuttler & Linz, 1980) of people recover or experienced mild end states (Ciompi, 1980), therefore, more than 50% of people diagnosed with schizophrenia recover without continuing symptoms or disability.

1) What are the positive aspects of schizophrenia and why is knowledge of them missing in the therapeutic milieu?

Have the genetics believed to be associated with schizophrenia persisted through generations of evolution because they strengthen the human gene pool in some important way? It is extremely difficult to identify literature discussing positive aspects of the experience or desirable qualities associated with the diagnosis of schizophrenia. Very few people; mental health professionals, consumers and the general public included would consider that there may be positive aspects to having schizophrenia.

Several epidemiological studies support the idea that people with schizophrenia have lower incidence of lung cancer despite an increased rate and amount of smoking (Lohr & Flynn, 1992; Barak & al., 2005; Hoffer & Foster, 2000). A recent meta-analysis of smoking and schizophrenia research found increased incidence and mortality rates for cancer in general but lower risk for lung cancer than expected (Bushe & Hodgson, 2010). Similarly, a decreased risk has been identified between schizophrenia and rheumatoid arthritis (Gorwood, 2004; Torrey & Yolken, 2001). Other epidemiological findings include having a higher pain tolerance, having fewer colds and 'flu, later greying of the hair, being more creative and artistic and having leadership qualities (Hoffer & Foster, 2000, Horrobin, 2002; Foster, 2003).

Chadwick (2009, p. 124) identifies the 'diagnostic gaze' as being incompatible with recognising the positive aspects of the experience of schizophrenia. Researchers are primarily engaged in identifying causes and manifestations of illness, rather than the positive aspects of illness or the causes and manifestations of wellness (Peterson & Seligman, 2004; Garmezy, 1971; Masten & Obradovic, 2006). Clinical and diagnostic frameworks derived through research reflect this view and set the

scene for illness-driven clinical interviews. There are encouraging signs that the re-engineering of the pessimistic world-view of mental illness into a wellness enhancing, strengths-based view has begun (see Schizophrenia Bulletin 2007, vol. 33, no. 1) (Chadwick, 2009; Frese, Knight & Saks, 2009) however the impact of this paradigm shift is yet to be felt on the clinical floor (Royal Australian and New Zealand College of Psychiatrists 2005; National Institute of Mental Health, 2009).

2) Why do clinicians demonstrate a pessimistic attitude towards the diagnosis of schizophrenia?

Literature supports the view that a prevailing pessimistic attitude has been in place over a long period of time by clinicians towards schizophrenia and the people diagnosed (Blueler, 1978; Chadwick; 2009; Cohen & Cohen; 1984; Leggatt, 2000; Kelly & Gamble; 2005; McCormack; 2007). There are several reasons for the pessimistic attitude remaining in place despite the existence of research identifying that up to 50% of people with schizophrenia recover with 30% of those achieving what is described as a successful outcome (Blueler; 1978; Ciompi; 1980; Huber, Gross, Schuttler & Linz; 1980; Harding, 2002).

Under the current biological medical model of treatment for schizophrenia, the person may become well but they have no idea why because they have had a very limited role in an outcome that has been largely determined by whether or not medication worked (Chadwick, 2009). Due to shortage of treatment resources, clinicians encounter schizophrenia at its most florid expression and can see that the illness may improve a little with medication but believe the person will never really be without symptoms of schizophrenia [Graybeal 2001, cited in Frese, Knight & Saks, 2009; Cohen & Cohen; 1984; McCormack, 2007). This has been called 'The Clinician's Illusion' and has been linked directly to the maintenance of the pessimistic view (Cohen & Cohen; 1984). The clinician's sense of hopelessness and powerlessness over the diagnosis can be transferred to the person being diagnosed (Leggatt; 2000; Kelly, & Gamble; 2005).

Mental health professionals have been vilified by people with schizophrenia and charged with generating experiences of hopelessness and helplessness through excluding the person and strictly adhering to the medication and monitoring practices of the medical model (Kelly & Gamble; 2005). Patricia Deegan, a consumer who experiences schizophrenia recounts how she was told at the time of her diagnosis that there was no hope of recovery but that through accepting treatment she could learn to adjust and cope with the disability for the rest of her life (Deegan; 1994). Stripping hope from a person through negative clinical language can lead to learned hopelessness (May; 2000).

Health services are seen to be promoting a positive, recovery based philosophy in policy and planning documentation but are not providing the resources necessary to carry this message through to the clinicians, consumers and their families and carers or to deliver changes to clinical practice, therefore the pessimistic view remains in place (Royal Australian and New Zealand College of Psychiatrists, 2005; National Institute of Mental Health, 2009; Commonwealth of Australia, 2008).

Results of the Vermont longitudinal study of the long-term course for schizophrenia correlated a hopeful view with positive health outcomes, symptom reduction and development of a future orientation (Harding & al., 1987). A sense of hope can support a person to take risks and to get back up again and have another go when an attempt fails (Kelly & Gamble; 2005). 'Hope connects someone directly to the dreamed-of future' (Peterson & Seligman, 2004, p. 519). Being seen as an individual, with strengths and capacity to love and find meaning and not defined as a set of symptoms, a disease or illness or a 'schizophrenic' is important (Kelly & Gamble; 2005). People who support others through believing and giving hope are supporting recovery (Ralph & Corrigan, 2005) and therefore this is an essential attitude for a clinician to hold in practice.

3) Is an optimistic outcome possible for schizophrenia?

Recovery from schizophrenia was in evidence through research from the early 1900's (Zinkin, 1950). Despite this early evidence for recovery, diagnostic criteria asserted that schizophrenia was incurable and therefore those that escaped diagnosis through demonstrating recovery were regarded to have been misdiagnosed. It wasn't until the criteria of 'incurability' was excluded from diagnosis in the 1950's, that illness-course investigations began, exploring the episodic nature of schizophrenia and also identifying recovery (Davidson & McGlashan, 1997). Interestingly, there have been reports of people recovering from schizophrenia after 30 to 40 years of symptoms (Huber, 1980; Barak & al., 2005) and perhaps it is a reflection on the limitations of research, rather than the limitations on the ability of individuals to recover that recovery has not been more widely explored and acknowledged.

While research evidence supports the possibility of a positive outcome for up to 50% of people diagnosed with schizophrenia, very little research has been conducted into how a person with schizophrenia arrives at a successful outcome from their illness experience. Recently published studies identified a non-linear staged process to recovering from schizophrenia which can result in a positive growth state or development of resilience for the individual (Andresen, Oades & Caputi; 2003; Tooth & al.; 2003; Geanellos, 2006). The study of successful developmental trajectories, particularly subsequent to encountering adversity is necessary for understanding, ameliorating and preventing psychopathology (Masten & Coatsworth, 1995). Knowledge about successful recovery from schizophrenia is required not to confirm that it happens, but instead to provide a guide and impetus for others to successfully recover, therefore further knowledge is required on the trajectory to successful recovery or resilient recovery with schizophrenia.

4) What is an optimistic outcome for schizophrenia?

Determining the specific qualities of an optimistic outcome for schizophrenia proved very difficult, primarily due to a lack of positively framed research. Consumer generated literature contained many examples of successful people who identified as having a diagnosis of schizophrenia, such as practicing psychiatrists, psychologists, sociologists, professors, lawyers, artists, musicians, writers and people in high government office (Frese, Knight & Saks, 2009). Many of these people studied and entered their professions subsequent to being diagnosed with schizophrenia. Worthy of consideration here is whether these individual's were able to access and use the positive aspects of schizophrenia, such as creativity and leadership skills, once they had their illness symptoms resiliently under control?

An optimistic outcome for a person with schizophrenia needs to be defined by that individual, rather than creating an artificially imposed, objectively derived set of standards that a person must meet to consider themselves to be recovered or to be successfully dealing with schizophrenia (Healy, Renouf & Ramon, 2007). Consumer Advocate Patricia Deegan [1994, p.55] defines recovery from a consumer pers-pective as;

'Recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again. The need is to meet the challenge of the disability and to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work and love in a community in which one makes a significant contribution.'

Resilience and growth were identified as the final stages of recovery in three separate studies on recovery from schizophrenia (Carver, 1998; Richardson, 2002; Andresen, Caputi & Oades, 2006).

5) How is an optimistic outcome achieved?

A literature review for 'resilience' revealed that the field of resilience research originated with the identification of children of parents with schizophrenia who grew to lead successful lives despite predictions that they would be dysfunctional because of their upbringing (Garmezy, 1971). Researchers wanted to know why these seemingly 'invulnerable' (later changed to 'resilient' (Luthar, 2006 in Cicchetti & Cohen) children emerged successfully. This finding signalled a fundamental shift in health research from studying the causes of illness to studying the causes of wellness.

If resilience is the ability to experience severely stressful events and not develop mental illness, then by definition, people who experience stressful events and develop schizophrenia are demonstrating vulnerability, rather than resilience; hence, they are 'vulnerable' people. Have the three studies that identified resilience as an outcome of recovery from schizophrenia also identified that a person is not purely born resilient but can also develop resilience in response to adversity? More importantly, what impact would the ability to develop resilience have on the experience of schizophrenia and the way that the journey with schizophrenia is understood?

A common interpretation of the meaning of resilience is one of "bouncing back", however this is aligned more with the concept of recovery (Bonanno, 2010). Resilience requires more than a return to original functioning and expects that additional experiences will be gathered to underpin the ability to grow after recovering functioning (Reich, Zautra & Hall; 2010). Resilience is more than having no symptoms but also involves 'a stable trajectory of healthy functioning across time' which includes the ability to grow new experiences or new relationships and to feel positive emotions (Bonanno, 2010, p. 21).

Resilient individuals respond to severe challenge or adversity with transient and mild disruptions to functioning, viewed as short-term dysregulation, which are brief, and the individual is usually able to continue to meet their responsibilities and maintain the capacity to grow (Bonnano, 2005; Wald & al.; 2006). This definition of resilience would accommodate the transient disruptions to functioning that might emerge as early warning signs for an episode of schizophrenia. A resilient person with schizophrenia would then respond by acting to restore equilibrium and avert an episode of psychosis.

A resilient individual has at their disposal, a number of supportive factors that are protective when risk or a significant threat is present and that buffer the individual against an adverse outcome (Masten & Obradovic, 2006; Masten, 2001). Factors found to be supportive or protective in the study of resilient children include the ability to form close, secure attachment to others, to engage the support of others, having good communication skills, an internal locus of control, low avoidance or distraction strategies (particularly into delusional ideation), having personal goals, the presence of an external support system, having problem solving skills, using self-discipline, having self-determination, a sense of humour, tolerance of negative affect and to view change or stress as a challenge or opportunity (Masten & al.; 1999; Rutter, 2006). These protective assets are not called into play until a significant risk or adversity presents (Masten, 2001). Certain factors or assets are known to exert a protective affect against developing schizophrenia however what is not well known or well researched, is what factors or assets exert a positive influence once schizophrenia has been developed, to buffer against future episodes of schizophrenia.

Evidence linking the development of resilience with schizophrenia to any specific characteristics, qualities, assets, factors or pathways cannot be identified, indicating a gap in literature and a research opportunity.

6) **How can this knowledge be used clinically to communicate the positive and optimistic aspects of undertaking the journey with schizophrenia?**

Further research to explore resilience in the context of schizophrenia, from the perspective of people who have successfully recovered from schizophrenia, may identify factors related to achieving a successful outcome, provide an idea of any processes or the pathway involved and also enable the construction of a clinical tool to provide a focus in clinical practice on promoting the positive aspects and optimistic potential for recovering resiliently on the journey with schizophrenia. Changed attitudes in mental health clinical practice towards a more optimistic and hopeful clinical experience is also a desirable outcome.

Research Question

What is the meaning of resilience for people who have experienced recovery from schizophrenia and how may resilience have been involved in their journey of recovery?

Research Aims

To obtain definitions of resilience from people who experience schizophrenia and to identify important factors related to recovery and developing resilience with schizophrenia to underpin creation of a tool to indicate how an individual with schizophrenia may move towards developing resilience and in so doing, underpin a positive interaction between clinician and consumer.

The research results will be published within a Doctoral Dissertation by the first author.

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